Stop the Stigma Campaign: How Language Shapes TB

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What is Stigma?

- “A mark of disgrace associated with a particular circumstance, quality, or person.” –Google

- “A sign or a mark that designates the bearer as spoiled and therefore as valued less than normal people.” –Goffman E. (1963)

How does a patient define stigma?
Synonyms for Stigma

- Scar
- Stain
- Blame
- Blemish
- Blot
- Brand
- Disfigurement

- Disgrace
- Dishonor
- Imputation
- Mark
- Taint
- Reproach
- Onus
Stigma Related Research

- Mental health
  - Substance abuse
  - Bipolar
  - Schizophrenia

- HIV/AIDS

- Tuberculosis
  - Swept out from under the rug!
How Can Stigma Affect Healthcare?

- Stigma is linked to poor health.
- Stigma is associated with greater social isolation.
- Social isolation increases risk for poor health outcomes.
- Stigma-health relationship is significantly strained after adjustment for social isolation.

How Can Stigma Affect TB Care?

- Contributes to a delay in diagnosis

- “At-risk individuals report that fear of TB stigma and the social and economic impact of stigma affects their willingness to undergo TB screening and to seek medical care after the onset of symptoms associated with TB.”

- “Individuals with TB and their health-care providers also identify TB stigma as a cause of non-completion of treatment.”

TB the Social Disease

“(Tuberculosis) is a social disease...its understanding demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body”.

- René Dubos (1901–82)
The Stigma of Tuberculosis

• “Fear of infection is the most common cause of TB stigma”

• By using non-stigmatizing language we can begin to breakdown the stigma associated with TB.
How Can Language Be Stigmatizing?

“Words are important. If you want to care for something, you call it a ‘flower’; If you want to kill something, you call it a ‘weed’.”

~ Don Coyhis
People First Language

Background:
People-first language avoids defining a person in term of his or her disability. In most cases, this entails placing the reference to the disability after a reference to a person, as in

“A person with a disability”

or

“A person living with a disability”

rather than

“the disabled person.”

The TB Suspect

• Suspect (verb)
  – To believe or feel that (someone) is guilty of an illegal, dishonest or unpleasant act, without certain proof

• Suspect (noun)
  – Person thought to be guilty of a crime or offense

• Why did the TB community decide to transfer the ‘suspicion’ of the disease to the patient?

R. Zachariah. INT J TUBERC LUNG DIS 16(6):714–717
The Defaulter

• What is default/a defaulter?
  – Oxford English dictionary
    • A person who fails to fulfill a duty, obligation or undertaking
  – Banking context
    • To fail to repay a loan
  – Legal context
    • Failure to appear in court when summoned by a judge
  – Context of competition
    • Failure to take part in or complete a scheduled contest

• Common feature:
  – blame is designated by someone in a decision-making position upon another in the community

R. Zachariah. INT J TUBERC LUNG DIS 16(6):714–717
Common Causes of ‘Default’

- Lack of regular, uninterrupted supply of drugs
- Patients having to pay for their drugs
- Lack of accessible ambulatory treatment centers in rural and urban settings (increased travel costs and time)
- Inconvenient clinic hours, long waiting times
- Lack of adequate numbers of motivated and friendly health workers
- Inappropriate patient education
- Lack of various alternative forms of treatment support (community, workplace or other)
- Lack of readily accessible joint HIV and TB services
Control

• National TB ‘Control’ Programs

• Control
  – To limit, regulate or restrict an activity or a process
  – To maintain influence and authority over behavior
  – Synonymous terms:
    • power, to dominate, and be in charge of

R. Zachariah. INT J TUBERC LUNG DIS 16(6):714–717
Control

• What is being controlled here?
  – TB? The patient? The affected community?

• ‘control of tuberculosis’ may inadvertently lead to programs trying to take control of tuberculosis patients by infringing on their rights and autonomy

• May be interpreted as something done to, rather than something done for, the patient

R. Zachariah. INT J TUBERC LUNG DIS 16(6):714–717
Who are our patients and what do we do for them?

• Are they defaulters?
  – Or are they lost to follow up?

• Are they TB suspects?
  – Or are they persons we suspect have TB disease?

• Do we ‘control’?
  – Or do we ‘care and prevent’?
Start of a Movement

“We all recognize the stigma our patients face - what I did not realize for too long is how I may have added to that with my words.”

–Barbara Seaworth, MD
(Medical Director, HNTC)
STOP THE STIGMA

Language in tuberculosis services: can we change in patient-centered terminology and stop the paradigm of blaming the patient?

A. Santiago, C. Tigges, J. Beachum, A. Suhaila, R. Duarte, F. Mokhtar, E. Santiago, E. Paniagua-Bejarano

STOP THE STIGMA

SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS (TB) CARE, COMMUNICATIONS AND PUBLICATIONS

STOP THE STIGMA

CIVIL SOCIETY CALLS FOR THE RETIREMENT OF STIGMATIZING AND CRIMINALIZING LANGUAGE FROM THE GLOBAL TB DISCOURSE

STOP THE STIGMA

I pledge to stop the use of language that is stigmatizing in the case of patients and their families affected by TB. Because #LanguageMatters, I will encourage others to #CommitToChange and #StopTheStigma by #SpeakingFromTheHeart.

I PLEDGED TODAY

STOP THE STIGMA

2015

Stop the Stigma
Make the Challenge

Our Challenge to You
Commit to using language that is patient centered, appropriate and sensitive and represents the dignity of people with TB and their families.

Sign the pledge: By signing the pledge, you are committing to stop the use of stigmatizing language when caring for persons and their families whose lives have been affected by TB. As a public health worker and leader in the field of tuberculosis, you pledge to adopt patient centered terminology that is appropriate, sensitive, and represents the dignity of people with TB and their families.

We will fill out a pledge card with your name on it and add it to other pledges. This banner is located at Heartland National TB Center on the campus of Texas Center for Infectious Disease a TB hospital located in San Antonio, Texas. This banner is visible to patients, health care workers, and visitors to the Heartland center.

Take a picture: Take a picture holding your “I Pledged” sign and email it to edgar.salinas@uthct.edu. We will add you to our Facebook page and Twitter feed.

Challenge others: Challenge others to join in your commitment. Let them know that you have made the commitment and would like to encourage them to do the same.

- Brochure
- Pledge Form
- Pledge Sign

Download and print the project brochure to display or present the project to your partners. Print a copy of the pledge form for them to sign and email to edgar.salinas@uthct.edu.
“Failure to consider stigma in theoretical and statistical models not only leads to an underappreciation of the social factors that produce poor health but can also undermine the efficacy of public health interventions.”

June 3, 2013
Heartland National TB Center
2003 SE Military Drive
San Antonio, Texas 78223

Dear [Speaker],

Thank you for your upcoming presentation at the upcoming (conference/training).

We would like you to be aware of HINTC’s commitment to join forces with patient advocates from the Global TB Community, the International Union Against TB and Lung Disease, and the National Society of TB Clinicians to eliminate stigmatizing language. The use of such language has been identified by TB survivors and others affected by TB as hurtful.

For additional information, please see the attached related article published in the International Journal of Tuberculosis and Lung Disease, a document on Language from Stop TB and the open letter to the Union regarding retiring stigmatizing and criminalizing language. Also attached is the response by Executive Director of the Union Dr. Jose Luis Castro.

Heartland would like to thank you in advance for your effort to support HINTC’s Commitment to eliminate the use of stigmatizing language. In parenthesis we have listed terms which have specifically been identified as hurtful and have noted suggested alternative language you may wish to use. Please review your slides and consider replacing the following terms: TB Defined (TB Care or TB Care and Prevention), Suspect (Possible TB disease or suspected TB disease). Default (Patient lost to follow-up), Non-compliant (Non-adherent), and TB Cases (patient(s) with TB disease). If you have any questions or concerns, please contact one of us to discuss further. Please note we will also review presentations prior to the scheduled presentation date to look for this terminology.

Thank you for supporting HINTC in this effort.

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#CommitToChange #TB
Special Thanks To:

Dr. Lisa Y. Armitige
THANK YOU